Influence of selected factors on the quality of dying and death in palliative care

(Wpływ wybranych czynników na jakość umierania i śmierci w opiece paliatywnej)

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Abstract – Introduction. The fundamental aim of palliative care is to achieve good quality of the process of dying and death. However, the interpretation of these issues remains unclear, mainly due to difficulty in determining the ultimate point of palliative care. That is why it is necessary to verify the constituents of the quality of dying and death. The aim of this study was to analyze the influence of selected factors on the quality of dying and death in the perspective of a "good death" in palliative care.

Materials and methods. The study is based on a literature review in the field of research on the evaluation of the quality of dying and death in palliative care. The following databases were searched: Pub Med (from 1973 to November 2015) and Web of Science (from 1974 to November 2015), using the key words *"quality of dying and death*" and *"good death*". Only the papers written in English and concerning the assessment of the quality of dying and death in palliative care have been taken into account. The following texts have been excluded: letters, case studies, editorials, and review articles as well as the papers on children and non-cancer patients.

Results. The studies carried out so far have distinguished a number of various factors affecting the quality of dying and death. Most of them are associated with health care system and include, among others: the timing of referral to a care facility, the availability of care, the management of symptoms, the type of therapy, communication. Other factors include the place of death, autonomy, preparation for death as well as sociodemographic factors.

Conclusions. From the point of view of the actors organizing and providing health care, it is important to understand such factors, which could then be modified so as to provide patients with high quality in terms of care as well as dying and death.

Key words **-** palliative care, quality of dying, quality of death, good death.

Streszczenie – Wstęp. Najważniejszym celem opieki paliatywnej jest osiągnięcie dobrej jakości procesu umierania i śmierci. Jednak interpretacja niniejszych zagadnień jest nadal niejasna, głównie z powodu trudności w określeniu, końcowego punktu opieki paliatywnej. W związku z tym konieczna jest weryfikacja składników jakości umierania i śmierci. Celem pracy była analiza wpływu wybranych czynników na jakość umierania i śmierci przez pryzmat „dobrej śmierci" w opiece paliatywnej.

Materiał i metody. Pracę przygotowano w oparciu o przegląd literatury z zakresu badań dotyczących oceny jakości umierania i śmierci w opiece paliatywnej. Dokonano przeglądu baz danych: Pub Med (od 1973 r. do listopada 2015 r.) oraz Web of Science (od 1974 r. do listopada 2015 r.) według słów kluczowych *„quality of dying and death" oraz „good death".* Do analizy zakwalifikowano wyłącznie prace w języku angielskim, które dotyczyły oceny jakości umierania i śmierci w opiece paliatywnej. Wykluczono prace o charakterze: listów, opisów przypadków, artykułów redakcyjnych i przeglądowych oraz te, które odnosiły się do dzieci oraz populacji pacjentów z chorobą nienowotworową.

Wyniki. W przeprowadzonych dotychczas badaniach wyróżniono szereg różnorodnych czynników wpływających na doświadczenie jakości umierania i śmierci. Najwięcej z nich związanych jest z systemem opieki zdrowotnej. Należą do nich między innymi: czas skierowania do placówki, dostępność opieki, kontrola objawów, rodzaj terapii, komunikacja. Do pozostałych czynników zalicza się miejsce śmierci, autonomię, przygotowanie do śmierci oraz czynniki społeczno-demograficzne.

Wnioski. Z punktu widzenia organizatorów i dostawców opieki zdrowotnej ważne jest poznanie tych czynników, które można modyfikować, tak aby zapewnić podopiecznym wysoką jakość opieki, oraz umierania i śmierci.

Słowa kluczowe **-** opieka paliatywna, jakość umierania, jakość śmierci, dobra śmierć.

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I. INTRODUCTION

In palliative care "the quality of life" refers to actions and experiences of patients in the final stage of an illness. It is not tantamount to the term "the quality of dying", where the emphasis is put on the experience with the preparation for death [1]. The quality of dying and death involves the degree of compatibility of a person's preferences as regards dying and the moment of death with other people's observations thereof [1,2].

The evaluation of preferences is the basis for a conceptual model of the assessment of the quality of dying. Particular attention should be paid to practical aspects and limitations on obtaining such information. First of all, it is difficult to determine the moment of death beforehand as the accuracy of disease prognosis is limited. Secondly, the patient's preferences may change just before death. What is more, it is estimated that approximately one in three people is not able to participate actively in an interview in the last week of life, and the reliability of the reports elicited from the caregivers several months after the death has not been thoroughly examined [1].

Moreover, the characteristics of the quality of dying may vary in different populations, and the experience of death may depend on the health care system, forms of care, social groups and cultural determinants [1]. The individual and dynamic character of the experiences of the terminally ill is a challenge, the overcoming of which plays a significant role in looking for social, organizational and individualized determinants of the quality of dying [3].

So far, several areas of the quality of dying and death have been defined. These include among others physical, psychological, social, spiritual, and existential experiences as well as the preparation for death and the circumstances of death [4].

The quality of dying and death also includes the term "good death" [5], which is of a complex, dynamic character and involves changes taking place in the whole process of dying [6]. It is tantamount to a natural process of passing away without human interference as a consequence of successful ageing [7].

The inseparability of the quality of dying and death and the notion of a "good death" leads caregivers to take into account the needs of the people being prepared for the forthcoming death [8,9,10]. This requires paying more attention to particular phases of dying and is an indispensable means of achieving [8] a good death by the patient and their family [9]. Vital components of this notion are dying with dignity, with the respect for autonomy, and in full consciousness [11], which corresponds with coming to terms with death [12]. Achieving a good death or a good dying process is the ultimate objective of palliative care. There are, however, few studies devoted to the influence of particular factors on improvement of the quality of dying [13,14,15].

The aim of the study was to analyze the influence of selected factors on the quality of dying and death in terms of a "good death" in palliative care.

II. MATERIALS AND METHODS

The study has been based on a review of the literature in the field of studies concerning the evaluation of the quality of dying and death in palliative care as well as "good death" in adults with neoplastic disease under palliative care. The following databases were searched: PubMed (from 1973 to November 2015) as well as Web of Science (from 1974 to December 2015), using the key words *"quality of dying and death", "good death", "good death in palliative care"*. Only research papers written in English were analyzed. The following texts were excluded: letters, case studies, editorials, and review articles.

III. RESULTS

On the basis of the analyzed texts, some factors affecting the quality of dying and death as well as good death have been identified, which were divided into several groups in the following areas.

The first group involves the factors associated with *health care system*. It was shown that it was not the duration of palliative care itself, but the duration of waiting for

care that had a great impact on the perception of the quality of dying and death [16,17]. Yamagishi et al. confirmed other authors' observations that a considerable number of patients had been referred for palliative care too late [16], which resulted in greater insatiability of the patients' needs, more anxiety and less satisfaction [17]; non-specialized care was related to worse preparation for death [18]. However, other studies prove that providing care for a period longer than 7 days is an important factor for good death [13].

The identified obstacles to achieving a "good death" include aggressive treatment e.g. chemotherapy within the last two weeks of life and prolongation of the treatment, which are considerable limitations to achieving a good death [15,19,20].

The following aspects are also emphasized: care available at night and on weekends, supervision by an attending physician as well as a team member in charge of care, which implies a higher quality of dying and death [3]. Achieving a "good death" is the dominant component of the care provided by medical staff both in hospices and palliative care. However, in order to achieve such a state, actions are required that integrate medicine and new technologies, motivate, outline the intellectual composition and prevent the routinization of the term "good death" [21].

Another group of factors involves the *place of death*, which had an impact on achieving a "good death" [14,22,23]. People who died at home among their relatives were characterized by a better quality of dying than those who passed away in a hospital or another care facility [22,24,25]. Home environment is the mainstay of the feeling of security, which reduces the patient's suffering by minimizing the therapeutic activity [26]. However, lower quality of dying and death in a hospital may result from the patient's clinical condition [25] accompanied by more severe health problems. It was observed that hospital death considerably limits the feeling of dignity, privacy and it quite often disturbs the consistency of care [20,27]. It also constitutes a departure from the natural dying process due to the use of various medical possibilities [20].

The results of the studies carried out in Taiwan, which aimed to find out the preferences for the place of death, revealed that a majority of caregivers had indicated the hospital as the place of the patient's death; however, a majority of patients had preferred to die at home [28]. It seems important to make a clear distinction between the preferences in regard to the place of death and the place of where care is provided, as well as to capture the evolutions of these choices in time [29].

Another group of factors are *evaluators*. The above-mentioned argument proves that the difficulty in interpreting the term "good death" by the evaluators is crucial in the analysis of the obtained results. The lack of objectivity makes the evaluators quite often pay attention to other constituents than the dying [30]. There are also discrepancies in assessing the circumstances of death. Patients expect a sudden death without suffering. The families, however, indicate a death that gives the opportunity to say goodbye and fulfill all the expectations of the final stage of dying [31,32]. However, eliciting information from a dying person may create a lot of difficulties [33], which may be dominated by some mind disorders resulting from cognitive disabilities [19,30,34].

Braun et al. conducted studies on quality of dying and death in a group of neoplastic patients in Israel. The analysis of sociodemographic factors of the bereaved caregivers revealed that those who were married tended to rate the quality of dying and death better than those who were not. This difference might be due to the fact that spouses spend more time together and that is why their observations are more accurate [25]. Women tend to report a better quality of dying and death than men. This might be due to women's greater commitment to care or else greater sense of fulfillment from the caregiving role [25]. Some authors also point to caregivers' cognitive capability. Hales et al. showed that cognitive functions disorders in some respondents made it impossible to interview them [35].

Studies by Cheng et al. carried out in Taiwan aimed at comparing the evaluation of the quality of dying by the bereaved family members and by the doctor taking care of the patient. The obtained results have proven that doctors rated the quality of dying and death higher than the bereaved family members did, which might have been associated with worse anxiety control and difficulty in verbal and non-verbal communication as attributed by the relatives [36].

Evaluation of a "good death" by nursing staff refers to the previous theoretical concepts. Several key constituents have been distinguished, such as symptom management, patient's autonomy, spirituality, the respect for dignity [37], relationships with team members [34,37,38], organization and the range of the provided care [37,39].

Attention should be paid to evaluation of attitudes towards the forthcoming death and values by the patients themselves as well as by their caregivers [22], which may be dominated by the stress experienced by relatives [15]. At the same time, caregivers point out that the dying person's experience forms their attitudes, which still may be different from the patient's actual point of view [40].

Factors associated with *the time of the evaluation*, at which the measurement is made [41,25], also appear to be significant. It seems necessary to determine such a time-

frame that will minimize the impact on the assessment that the mourning by the bereaved caregivers can have. A study conducted in Taiwan may serve as an example, where a group of 570 bereaved caregivers were asked to give an assessment within the period from 2 to 6 months after the patient's death. In Korean culture, the period of two months was assumed to be sufficient to come to terms with the death of a close family member and return to "normal" life [41]. However, other studies revealed that the most frequent reason for refusing to participate in the study was the bereaved caregivers' emotional difficulty, which made it impossible to interview them despite the fact that the evaluations had been planned between the 8th and 10th month after the patient's death [25].

However, in the literature on the subject, there has been no information concerning the relationship between the duration of the period of time from the patient's death to the moment of evaluation and the quality of dying and death [3].

The essential group of factors determining a "good death" concerns the person of the *patient*. In one of the analyses, 5 areas have been distinguished, which constitute the symmetry of the patient's biopsychosocial dimensions. Thus the preparation for death involves: physical comfort [30,32], spiritual comfort [31], family [30,34], social relations [30] and the moment of death [30,32]. The said areas correspond with relieving persistent physical symptoms and relieving pain [34,42,43], which affect the suffering experienced by a dying person [44].

While analyzing the variables affecting the quality of dying in the context of the person of the patient, the role of autonomy should be emphasized [30,40,37,33]. It is the foundation of the comprehensive care along with the respect for privacy [31], the respect for dignity [34,40,43], the acceptance of death as a natural stage of life [40,45,15,22,46] and sustaining hope [19,30,45].

Patient's autonomy is an essential constituent of the measurement tools for the quality of dying. It is emphasized that maintaining the feeling of being in control has a considerable influence on ensuring death with dignity [13,47]. The results of the studies conducted in Japan also put emphasis on the meaning of good relationships within the family and the feeling of not being a burden to others [34].

The study carried out in the United States in a group of 158 bereaved caregivers demonstrated that most of them responded that the dying person's will had been fulfilled; but in regard to the people whose will had not been fulfilled, there was a greater probability of a bad death. Moreover, people experiencing pain, anxiety and stress equated their own feelings with bad death [48].

The final stage of life provides a room for changes, which will enable to work out standards improving the quality of dying and death. Simultaneously, "good death" is equivalent to a death coherent with the patient's personality. Thus a frame of a "good death" should be determined taking into account a model of passing away that is conscious, autonomic and communicative. At the same time, the role of the communication between the patient, the family and the medical staff [42,40,49,20] is emphasized as this gives a feeling of community [30], independence, control [50] and satisfaction from the provided care [23].

Listening, explaining the patient's health condition and communicating at the level comprehensible for the patients and their caregivers is connected with the higher quality of dying and death [3]. On the other hand, receiving discrepant information from health care professionals was more often related to a worse evaluation of death [48].

Another important factor affecting the quality of dying patients' experiences is their *age*. Cheng et al. carried out a study in a group of 2,375 patients, where the opinions of the members of the care team were used to assess the quality of dying. A multivariate regression analysis has revealed that the patients' age between 40 and 65 is an essential factor for good death [13].

Other studies demonstrate that older people seem to show greater preparedness for death and a lower level of anxiety in comparison to younger people [15,46]. Age was also related to severity of physical symptoms. Older people suffered from a more severe dyspnea, fatigue, and emotional stress as compared to the younger ones. However, opposite results were obtained as regards pain severity [51].

One of the studies by Cheng et al. points out the impact of the physical and psychological condition on the degree of independence in the elderly. Moreover, the degree of consciousness, the level of acceptance of the end of life, the respect for dignity, the relationship with the medical staff were inseparable components of a "good death" in the elderly [38].

The findings of the study by Del Vecchio Good et al. reveal that in people aged above 65, the process of dying is disturbed mainly due to the excess of medical interventions [38].

IV. SUMMARY

Health care professionals providing care to neoplastic patients have long been interested in ways to diminish their suffering and to improve the quality of care in the final stage of life [48]. However, in order to improve the quality of dying and death, one should understand first what contributes to good or bad death. Those in charge of organiz-

ing and providing health care are particularly interested in clinically significant factors which may improve the quality of the experiences of the dying and which can be modified. These include: the quality of communication in the patient – service provider (doctor, nurse) relationship, pain and symptomatic treatment, the timing of referral to a hospice or other forms of palliative care [48].

Better quality of dying and death involves such factors as: the proper management of pain and other accompanying symptoms, the respect for the patient, the trust in health care, the preparation for death [48].

The results obtained in numerous studies emphasize the role of a "good death", which should be based on individual preferences regarding death as well as cultural determinants. One of the key observations of a "good death" is the acceptance of the way of dying, keeping the belief in values held by each individual [52].

While considering the issue of death, one cannot ignore the medicalization of the process of dying, which is connected with technological advancement on two extremes [53,54]. This connection is on the one hand helpful in improving the process of dying , and on the other hand, it may pose a danger in terms of dehumanization. Moreover, it may pose the real danger of prolonging the process of dying, thus denying "good death". Therefore, palliative care has been faced with an enormous challenge that consists in not losing the holistic approach to a terminally ill person despite the technological progress.

V. CONCLUSIONS

1. Among the factors affecting the quality of the experience of dying persons, one should differentiate between those which form the evaluators' opinions (e.g. respondents' cognitive disorders, gender, the type of relationship) and those which may have a real connection with the patients' experiences (e.g. the quality of communication, autonomy, the preparation for death, fulfilling the patient's will).
2. From the point of view of the actors organizing and providing health care, it is important understand the factors which may be modified so as to provide the patients with high quality care, and consequently, high quality of dying and death.
3. Achieving a "good death" is the ultimate aim of palliative care, which requires a more thorough analysis of the dominant factors.
4. Due to the limited number of publications in the subject of the quality of dying and death as well as "good death", it seems to be necessary to undertake further research in this field.

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